Is South Africa winning?

Taking stock of the response to children, PMTCT, adolescents, prevention, treatment, retention in care, TB, palliative care, pain control…
**HIV and TB: Facing up to the current challenges**

Ten years ago on 19th November 2003 the late Dr Manto Tshabalala-Msimang made public South Africa’s first plan to treat people with HIV using anti-retroviral (ARV) medicines. The announcement came in the face of up to 1 000 AIDS-related deaths a day. It was after a persistent campaign led by the Treatment Action Campaign (TAC) and its allies.

Tshabalala-Msimang, former President Thabo Mbeki, former health Director General Thami Mseleku and their cronies never believed in the treatment plan – and did all they could to frustrate its implementation. But the dam wall had been breached and TAC’s campaigns to promote treatment, later fully supported by Health Minister Dr Aaron Motsoaledi, led to a steady growth in numbers of people on ARVs.

Ten years later there are well over two million people taking ARV treatment – the exact numbers are uncertain and that is one of the matters we take issue with in this edition of the NSP Review. Life expectancy has increased, some say by up to ten years. AIDS related mortality has come down dramatically, but at over 150 000 deaths a year is still very high. And mother to child transmission of HIV, the challenge with which TAC launched its first campaign in 1999, is down to 2.7% of HIV pregnancies at 6 weeks post birth.

All very good news indeed and we salute our government and our public health workers for such a remarkable turn around. However TAC and SECTION27 are not part of the clapping classes. From the outset we have fought for quality health care services and sustainable treatment programmes. We have fought for the rights of every person with HIV and will not stop at ‘a lot of people with HIV’. It is for this reason that this NSP Review aims to cause alarm about aspects of our response to HIV and TB – because alarm is warranted. UNAIDS with its love of slick and sometimes misleading slogans talks of ‘Getting to Zero’ and South Africa has adopted this language. But we are concerned that ‘key populations’, sex workers and prisoners in particular get little more than lip services in programming.

Sometimes what we describe are hairline fractures, but sometimes they are cracks, and sometimes they are gaping chasms. They all need action.

Until they get this action we will grade South Africa’s response to HIV as a C. Denial of the existence of HIV may be over; denial of access to ARVs might be a thing of the past; ‘a lot of people with HIV’ and will not stop at ‘a lot of people with HIV’. It is for this reason that this NSP Review aims to cause alarm about aspects of our response to HIV and TB – because alarm is warranted. UNAIDS with its love of slick and sometimes misleading slogans talks of ‘Getting to Zero’ and South Africa has adopted this language. But we are concerned that ‘key populations’, sex workers and prisoners in particular get little more than lip services in programming.

We unapologetically focus on the fault lines in the implementation of the NSP and will continue to do so in 2014:

- Perhaps the biggest challenge facing us are stock-outs, which an investigation and report by the Stop Stock-outs Project (SSP) shows have reached extreme danger levels and may be directly affecting up to half a million people living with HIV.
- Integraly linked to this problem is the almost non-existent qualitative monitoring of the ARV programme – a threat and a travesty after 10 years and now that so many people are on treatment;
- We argue that South Africa is not making progress against TB;
- But we also describe growing concerns about the overall state of the health system, as reflected in our report on the crisis in Gert Sibande, an NHl pilot district in Mumpamula and the district with the highest HIV prevalence in the country;
- We are concerned that ‘key populations’, sex workers and prisoners in particular get little more than lip services in programming.

**“Sometimes what we describe are hairline fractures, but sometimes they are cracks, and sometimes they are gaping chasms. They all need action.”**

**NSP Review #9 2013**
The South African government has the HIV epidemic under control, according to the Minister of Health, Dr Aaron Motsoaledi. Recent statistics, he says, support his claim: 2.1 million people are on antiretroviral treatment (up from 923,000 in 2009), 3,540 HIV treatment sites have been established (up from 490 in 2009), and 23,000 nurses are able to initiate patients on treatment, compared to 250 four years ago.

Speaking exclusively to the NSP Review, Motsoaledi acknowledges that there are challenges. “We do experience logistical problems when it comes to drug distribution, but it is important to note that these stock-outs are sometimes caused by industry,” he claims.

Gauteng has managed, he says, to double the number of people on treatment from 250,000 to half a million, despite serious obstacles.

Quizzed about levels of retention in care, Motsoaledi responds that South Africa’s monitoring systems are successful and indicate positive trends. “If you want to know whether people are accessing treatment and managing to stay on this treatment, you can look at our life expectancy figures that are increasing. I think the figures answer that question,” he says.

“If people were still dying in large numbers we would be seeing it… Our monitoring systems are not picking up such trends. In fact, the number of people dying has decreased markedly,” Motsoaledi believes the rollout of fixed dose combination antiretroviral treatment will raise adherence levels further.

He predicts that forthcoming data from the prevention of mother-to-child transmission (PMTCT) programme are likely to show that HIV transmission rates have declined further from the current level of 2.7%.

“All the indications are there that we are making progress. (This shows) that our HIV programmes have turned the corner,” he says. Motsoaledi acknowledges, however, that getting people to take an annual HIV test is difficult.

When asked to comment on the success of the South African National AIDS Council (SANAC), he says that the organisation has played an important role in mobilising civil society, but declines to be drawn further on whether he believes SANAC is fulfilling its mandate. Properly-functioning AIDS Councils are critical to the success of the National Strategic Plan and KwaZulu-Natal’s achievements (in managing/treating HIV?) need to be replicated, he says.

Motsoaledi acknowledges that he is deeply worried about the high incidence of TB in the country. BRICS nations such as South Africa carry a high burden of TB and account for 60% of drug-resistant TB cases. He believes though that we are making progress. “We have increased the TB cure rate tremendously and I think the GeneXpert (testing system) has played a role in that. We have 80% coverage and (aim to achieve) 100% coverage by the end of this financial year.”

The Minister reveals that teams of health workers are screening family members their homes, where TB has been diagnosed and 150,000 families have been visited. This has led to 3,000 new diagnoses.

Progress is also being made in treating TB in prisons. Since the launch of the [new TB in prisons] guidelines on World TB Day in March, six regions have started using GeneXpert testing to screen inmates upon arrival and twice a year while incarcerated, says Motsoaledi.

In Pollsmoor Prison in Cape Town, 12,000 inmates have been screened, with 175 testing positive and placed on treatment. The families of prisoners have also been followed up.

Motsoaledi says that South Africa now needs to focus on TB in the mining sector. Money from The Global Fund to Fight AIDS, Tuberculosis and Malaria will fund the screening of 100,000 workers at smaller mines, while government money will help to screen 500,000 people at larger mining sites. Motsoaledi says this [new] drive is part of an effort to monitor compliance by the mining companies when it comes to their workers. The results of the programme will be announced at an international mining conference in February next year.

When Dr Aaron Motsoaledi was appointed health minister in May 2009, the country was slowly emerging from a dark and sad time in the government’s response to HIV. NSP Review had 30 minutes with the Minister to pose a number of burning questions on the HIV programme.

“"If people were still dying in large numbers we would be seeing it..."”

Photo by Robert Hamblin
NEWS – ARV RETENTION IN CARE

Losing patients

Mara Kardas-Nelson

Within just over a decade, South Africa’s handling of its HIV crisis has seen the country transformed from an international pariah to a leader. Once known for denying HIV treatment to its citizens, the country now boasts the largest treatment programme in the world: over two million South Africans, it is claimed, are on anti-retroviral therapy (ART). This dramatic total is impressive. It is also not accurate.

According to Dr Leigh Johnson, an epidemiologist at the University of Cape Town's Centre for Infectious Disease Epidemiology and Research, South Africa's national figures reflect the total number of people who have ever been initiated on treatment, but very importantly not those currently in care.

Providing a more precise estimate of how many people are on ART is difficult. The quality of data is often poor, and monitoring and evaluation systems are compromised by human errors and outdated methods of collation. Much of the information the country gathers is still done using paper-based systems.

Furthermore, the country's population is highly migratory and people move regularly between towns and between health centres. The health system is poorly integrated so keeping track of people is challenging. Miscounting is inevitable. South Africa may know the approximate number of all South Africans who have ever been placed on treatment, but it is much less certain how many are still taking their ARV drugs. Even less certain is how many people have been tested for HIV, but have never returned to receive treatment.

According to Richard Lessells, a researcher with the Africa Centre for Health and Population Studies at the University of KwaZulu Natal and the London School of Hygiene and Tropical Medicine, losing people from the system is undoubtedly one of the biggest challenges … if we’re serious about trying to reduce [the] transmission of HIV, then long-term retention is more and more important.”

Lessells has studied retention in care. His findings, and those of other researchers, point to worrying trends. For example, a systematic review of African studies of retention in care, published in PLoS Medicine in 2011, found that only one-fifth to one-third of HIV patients remained continuously in care from the time they were tested to the time they were placed on long-term ARV treatment.

“...only one-fifth to one-third of HIV patients remained continuously in care from the time they were tested to the time they were placed on long-term ARV treatment.”
Losing patients continued

Drug stock-outs, however, are solvable and avoidable. In the past year, every province has experienced stock-outs to varying degrees, according to Monique Linares of the Stop the Stock-outs Project. Along with partners, the group regularly monitors stock-outs across the country. When they occur, patients are unable to obtain their medicines, leading to confusion and frustration. Some patients find replacement medicines. Others face treatment interruptions or, worse still, are forced to go without treatment entirely. “That’s one area where we have control,” says Venter. “The government absolutely needs to prioritise [it] … It’s much easier to control [stock-outs] than dealing with the psychology of someone who has a chronic disease and convincing them to stay in the system.”

Shifting priorities of one of South Africa’s largest donors poses a new threat to retention in care for some patients. The US President’s Emergency Plan for HIV/AIDS (PEPFAR) has been instrumental in placing a significant percent of South African HIV patients on ART. PEPFAR’s priorities, however, are shifting away from emergency responses or, worse still, are forced to go without treatment entirely. “That’s one area where we have control,” says Venter. “The government absolutely needs to prioritise [it] … It’s much easier to control [stock-outs] than dealing with the psychology of someone who has a chronic disease and convincing them to stay in the system.”

Matthew Kavanagh of the US-based advocacy group Health Gap is less optimistic. He believes that between 50,000 to 200,000 patients were lost as they were shuffled from PEPFAR sites to public clinics. This data is based on a study considering patients who transition from the PEPFAR-supported McCord Hospital in Durban to public facility. “19% didn’t make their first visit,” Kavanagh observes. Kavanagh notes that his estimated numbers do not include patients who have been tested but have not yet received ART. “There were thousands and thousands of people who were in pre-ART care at the PEPFAR-funded sites. God only knows where they are now.”

Efforts by NSP Review to get comment from the Department of Health were unsuccessful.

An MSF doctor consults a patient at their clinic next to the Central Methodist church in Johannesburg.

Anso Thom, SECTION 27

South Africa is roundly praised for the rate of mother-to-child transmission which has plunged from 8% in 2008 to an estimated 2.7%, in 2011 (Medical Research Council survey) and is continuing to fall. However, experts are questioning whether this indicator is able to provide us with important information about postnatal HIV transmission, the transmission that happens once the baby has been born HIV-negative.

Dr Andrew Boulle, an HIV specialist at the University of Cape Town, says that the key message is encouraging that there has been a dramatic decline in in-programme transmission. He adds that in the Western Cape “half of our new diagnoses are made in hospitals in sick children who are not measured by the PMTCT (prevention of mother-to-child transmission) programme.” “It is still a great success, but there is more to still be done than is apparent from the routine programme data.”

“As we get to these low numbers of transmissions, the relative importance of the pockets of missed patients become more important. Even if 5% of HIV-infected patients skip HIV testing, given the 10 times higher transmission without prophylaxis, they could contribute an extra 50% of infections not measured by the PMTCT programme.”

Experts agree that postnatal transmission is an important area of concern. Dr Vivian Black Director for Clinical Programmes at the Wits Reproductive Health and HIV Institute says that it is important for us to start reaching children who are not being tested at six weeks.

She agrees that it is very clear that we do not know what the health outcomes are for infants after six weeks. The lack of mother and infant follow-up is a massive weakness in South Africa’s PMTCT programme. If we are to fully realise the objectives of the NSP, then addressing this issue is critical. Dr Leigh Johnson, an epidemiologist from the University of Cape Town, says that none of the indicators we have “tell us anything about the extent of postnatal transmission (transmission through breastfeeding).” Although it’s very encouraging that we’ve made so much progress in reducing perinatal transmission (immediately before and after birth) Johnson says, “It’s worrying that we have so little information on the extent of postnatal transmission.” Researchers have attempted to conduct postnatal follow up of HIV exposed infants who tested HIV negative at six weeks in order to measure postnatal transmission but maintaining a large cohort of infants across all nine provinces, where high mobility of mothers and infants is common, is challenging and expensive. Considerable challenges remain

Writing in the District Health Barometer, Linda Mureithi from the Health Systems Trust, and Professor Gayle Sherman from the National Health Laboratory Service, caution that despite the success of South Africa’s PMTCT programme so far, we still face considerable implementation challenges. Important components need improvement, such as ensuring early antenatal clinic attendance and early infant diagnosis, the integration of PMTCT services into primary health care, and the provision of antiretroviral (ART) services to patients diagnosed with HIV. Data quality must also be improved in order to monitor progress.

Current polymerase chain reaction (PCR) testing at six weeks mainly identifies perinatal transmission – the HIV transmission that happens before or during birth. Babies born to HIV positive mothers typically test HIV-positive on a standard antibody test because their blood contains HIV antibodies from their mothers for several months after birth. For this reason, babies are given a special PCR test that can identify HIV in the blood within the two to three weeks of infection and therefore determine whether they themselves have HIV.

Johnson says that data from the District Health Barometer does not tell us enough about the proportion of HIV-positive mothers receiving different forms of antiretroviral prophylaxis almost entirely and perinatally (and how this impacts on transmission rates).

The District Health Barometer 2012/13 gives a coverage rate of 82% for ART in pregnancy which appears to be an over estimate – the SAPMTCTE (South African PMTCT Evaluation) survey found 46% ART coverage in 2011.
Dr Ameena Goga, one of the main authors of the SAPMTCTE and Specialist Scientist at the Medical Research Council shares Johnson’s concerns. She says that data from the National PMTCT evaluation (still in the process of being published as peer-reviewed papers) shows that:

- South Africa has reduced early (4-8 week) transmission to 3.5% with dual therapy introduced in 2008 and to 2.7% with an improved PMTCT regimens introduced in 2010.
- Acquisition of HIV infection during pregnancy is high – in 2010 and 2011 surveys 4% of mothers reported negative but had HIV exposed infants by six weeks post-delivery.
- Transmission seems similar between mothers receiving longer term dual prophylaxis and ART (i.e triple therapy as treatment).

Although South Africa has introduced the new ART regimen in April 2013, Dr Goga notes that its effects on mother-to-child transmission are still unknown. She cautions that rather than looking at transmission only, “we really need to look at child survival and in future need to add child development. I think this should always be a very strong message as we aim to build future generations.”

Reaching a plateau

Dr Goga believes that South Africa will reach a plateau shortly at which greater and perhaps different investment will be needed to achieve further reductions in transmission. “It’s not only about the drug regimen, but co-morbidities; placental factors and so on will start coming into play as soon as the bulk of transmission is reduced. There is little available data showing what happens after six weeks post-delivery.

Goga notes that researchers are beginning to investigate such issues. In an article published in the journal *AIDS* this year, for example, Kate Kerber and colleagues sought to analyse trends in the mortality rate of under-5s in South Africa (1990-2011), and the contribution of AIDS in particular to those deaths. Estimates were reviewed using three nationally-used models for estimating the number of AIDS deaths in children.

Although different results were reported for each model, the trends revealed were similar, and showed that the mortality rates peaked at around the year 2005. AIDS as a cause of child deaths peaked between 37% and 39% in the period 2004-2005, and this level has since declined.

South Africa was one of only four countries in 2005 with a mortality rate for under-5s that was higher than the 1990 Millennium Development Goal baseline. In the past five years, the country has achieved a rate of reduction of child mortality exceeded by only three other countries.

The researchers ascribe this rapid success to the scale-up of South Africa’s PMTCT programme and, to a lesser degree, the expanded roll-out of ART.

“Emphasis on these programmes must continue, but failure to address postnatal transmission as well as other aspects of care including integrated high quality maternal and neonatal care means that the decline in child mortality could stall,” they add.

Breastfeeding is still the recommended feeding choice for all mothers, including those who are HIV-positive. South Africa’s exclusive breastfeeding rate is among the bottom ten globally and has suffered from mixed messages around best practices. “We all agree that postnatal transmission is now going to be the next big issue to tackle, but hopefully we can do so without confusing the breastfeeding messages again,” adds Kerber.

While there is agreement that South Africa’s PMTCT programme is a best practice model, many questions remain as to what happens once the mother has given birth – in essence we know very little.

“As we get to these low numbers of transmissions, the relative importance of the pockets of missed patients become more important.”

“AIDS this year, for example, Kate Kerber and colleagues sought to analyse trends in the mortality rate of under-5s in South Africa (1990-2011), and the contribution of AIDS in particular to those deaths. Estimates were reviewed using three nationally-used models for estimating the number of AIDS deaths in children.

Although different results were reported for each model, the trends revealed were similar, and showed that the mortality rates peaked at around the year 2005. AIDS as a cause of child deaths peaked between 37% and 39% in the period 2004-2005, and this level has since declined.

South Africa was one of only four countries in 2005 with a mortality rate for under-5s that was higher than the 1990 Millennium Development Goal baseline. In the past five years, the country has achieved a rate of reduction of child mortality exceeded by only three other countries.

The researchers ascribe this rapid success to the scale-up of South Africa’s PMTCT programme and, to a lesser degree, the expanded roll-out of ART.

“Emphasis on these programmes must continue, but failure to address postnatal transmission as well as other aspects of care including integrated high quality maternal and neonatal care means that the decline in child mortality could stall,” they add.

Breastfeeding is still the recommended feeding choice for all mothers, including those who are HIV-positive. South Africa’s exclusive breastfeeding rate is among the bottom ten globally and has suffered from mixed messages around best practices. “We all agree that postnatal transmission is now going to be the next big issue to tackle, but hopefully we can do so without confusing the breastfeeding messages again,” adds Kerber.

While there is agreement that South Africa’s PMTCT programme is a best practice model, many questions remain as to what happens once the mother has given birth – in essence we know very little.”

Reaching a plateau

Dr Goga believes that South Africa will reach a plateau shortly at which greater and perhaps different investment will be needed to achieve further reductions in transmission. “It’s not only about the drug regimen, but co-morbidities; placental factors and so on will start coming into play as soon as the bulk of transmission is reduced. There is little available data showing what happens after six weeks post-delivery.

Goga notes that researchers are beginning to investigate such issues. In an article published in the journal *AIDS* this year, for example, Kate Kerber and colleagues sought to analyse trends in the mortality rate of under-5s in South Africa (1990-2011), and the contribution of AIDS in particular to those deaths. Estimates were reviewed using three nationally-used models for estimating the number of AIDS deaths in children.

Although different results were reported for each model, the trends revealed were similar, and showed that the mortality rates peaked at around the year 2005. AIDS as a cause of child deaths peaked between 37% and 39% in the period 2004-2005, and this level has since declined.

South Africa was one of only four countries in 2005 with a mortality rate for under-5s that was higher than the 1990 Millennium Development Goal baseline. In the past five years, the country has achieved a rate of reduction of child mortality exceeded by only three other countries.

The researchers ascribe this rapid success to the scale-up of South Africa’s PMTCT programme and, to a lesser degree, the expanded roll-out of ART.

“Emphasis on these programmes must continue, but failure to address postnatal transmission as well as other aspects of care including integrated high quality maternal and neonatal care means that the decline in child mortality could stall,” they add.

Breastfeeding is still the recommended feeding choice for all mothers, including those who are HIV-positive. South Africa’s exclusive breastfeeding rate is among the bottom ten globally and has suffered from mixed messages around best practices. “We all agree that postnatal transmission is now going to be the next big issue to tackle, but hopefully we can do so without confusing the breastfeeding messages again,” adds Kerber.

While there is agreement that South Africa’s PMTCT programme is a best practice model, many questions remain as to what happens once the mother has given birth – in essence we know very little.”

Reaching a plateau

Dr Goga believes that South Africa will reach a plateau shortly at which greater and perhaps different investment will be needed to achieve further reductions in transmission. “It’s not only about the drug regimen, but co-morbidities; placental factors and so on will start coming into play as soon as the bulk of transmission is reduced. There is little available data showing what happens after six weeks post-delivery.

Goga notes that researchers are beginning to investigate such issues. In an article published in the journal *AIDS* this year, for example, Kate Kerber and colleagues sought to analyse trends in the mortality rate of under-5s in South Africa (1990-2011), and the contribution of AIDS in particular to those deaths. Estimates were reviewed using three nationally-used models for estimating the number of AIDS deaths in children.

Although different results were reported for each model, the trends revealed were similar, and showed that the mortality rates peaked at around the year 2005. AIDS as a cause of child deaths peaked between 37% and 39% in the period 2004-2005, and this level has since declined.

South Africa was one of only four countries in 2005 with a mortality rate for under-5s that was higher than the 1990 Millennium Development Goal baseline. In the past five years, the country has achieved a rate of reduction of child mortality exceeded by only three other countries.

The researchers ascribe this rapid success to the scale-up of South Africa’s PMTCT programme and, to a lesser degree, the expanded roll-out of ART.

“Emphasis on these programmes must continue, but failure to address postnatal transmission as well as other aspects of care including integrated high quality maternal and neonatal care means that the decline in child mortality could stall,” they add.

Breastfeeding is still the recommended feeding choice for all mothers, including those who are HIV-positive. South Africa’s exclusive breastfeeding rate is among the bottom ten globally and has suffered from mixed messages around best practices. “We all agree that postnatal transmission is now going to be the next big issue to tackle, but hopefully we can do so without confusing the breastfeeding messages again,” adds Kerber.

While there is agreement that South Africa’s PMTCT programme is a best practice model, many questions remain as to what happens once the mother has given birth – in essence we know very little.”

Health system failing to track babies after birth

Continued
TB: Tackling an orphan disease

Professor Nulda Beyers, Desmond Tutu TB Centre, Stellenbosch University

Tuberculosis (TB) is (1) the leading cause of death in South Africa and (2) a public health crisis. Most of the TB deaths are preventable and the public health crisis should be managed by decreasing transmission of TB. Political will, commitment and visible leadership are therefore urgently needed to manage this health crisis that is out of control.

While TB rates are decreasing worldwide, including in Africa, the World Health Organisation’s Global Tuberculosis Report 2013 notes that the estimated TB incidence in South Africa – already unacceptably high for many years – has continued to increase. TB incidence in South Africa is now estimated to be more than 1,000 cases per 100,000 people while in countries like USA, Japan, Australia and many countries in Europe it is less than 10 per 100,000. In addition, South Africa is one of three countries (together with India and Ukraine) with the largest increases in multidrug-resistant tuberculosis (MDR-TB) between 2011 and 2012.

The causes of the recent increases in TB in South Africa are complex, and addressing these problems requires a clear framework of action in which research findings inform the actions of the South African government.

The first of the actions we need to take is to identify and treat the cases that have been missed. According to the World Health Organisation Global Tuberculosis Report 2013 “about 75% of the estimated 2.9 million missed [TB] cases – [i.e.] people who were either not diagnosed or diagnosed but not reported to National Tuberculosis Programmes (NTPs) – were in 12 countries; of which South Africa is one. The percentage of cases on treatment in South Africa has been estimated to be (as low as) 22%. This is because many people who have TB symptoms do not access healthcare services, and many of those who do access the healthcare system with symptoms of TB are not tested. It is estimated that in South Africa, a quarter of people who are diagnosed with TB are never started on treatment. The gap in treatment coverage for detected cases of MDR-TB is also continuing to widen. The inability of health services to provide adequate follow-up and treatment is both cost inefficient and a poor use of health service resources. It may also be regarded as an ethical and professional failure.

The second action we need to take is to increase the amount of funding for TB services. While it is encouraging that new diagnostic tools are available, these are expensive. Careful evaluation of new approaches is needed within the context of South Africa-specific operational research. A commitment from the government to fund such research should be given, as well as a commitment to using the findings from such operational research to bring about changes in policy, management, and practice.

Finally, gaps in the provision of basic healthcare must be addressed as a matter of urgency, and raising awareness of current weaknesses is important. Politicians should be encouraged to raise awareness of TB as a health crisis by talking publicly about TB and challenges in the health services more often. Lastly, there is an urgent need for proper governance and management in the health services, including the need for skills training and personnel deployment.

Overcoming our current challenges is important because it is the constitutional duty of the South African government to ensure that its expenditure on healthcare is cost-effective, that structures are in place to monitor and govern health service delivery, and that healthcare workers have the appropriate clinical and managerial skills. As Sections 27 and 28 of the Constitution specify, it is the duty of the state to ensure that “everyone has the right to access to health care services” and that “every child has the right to basic health care services… ” and “to be protected from maltreatment… ”

A failure to diagnose and treat TB in adults leads to ongoing transmission and places children at greater risk of contracting TB. This may be interpreted as a further potential failure on the part of the state to meet its constitutional obligations. At the same time, it is the responsibility of all healthcare workers, as public servants, to ensure that the constitutional rights of children are respected. This can be done by ensuring that all children and adults with TB are diagnosed and treated. The importance of upholding the rights of children is a particularly strong and positive incentive for the state to succeed in combating the current TB epidemic. As the WHO data indicates, urgent action is needed.

“TB incidence in South Africa is now estimated to be more than 1,000 cases per 100,000 people”
Quality goes down as quantity goes up

Amir Shroufi & Gilles van Cutsem, Médecins Sans Frontières South Africa (Doctors without Borders)

"When you know better you do better"
Maya Angelou, celebrated civil rights activist and poet

Do we know what is going on with South Africa’s antiretroviral programme? Can we do better?

Despite the fact that this is the world’s largest antiretroviral treatment (ART) programme, detailed data on its performance are hard to find, and evaluations on the quality of the existing data even harder. When attempted, use of external data sources to verify plausibility of reported statistics provided inconsistent results1.

In short, in order to scale up without messing up, increased attention is needed towards quality monitoring and evaluation. At the very least we should know how many were started on ART, how many are retained, and how many of these have an undetectable viral load.

**SO WHAT DO AND DON’T WE KNOW ABOUT THE LARGEST ANTIRETROVIRAL PROGRAMME IN THE WORLD?**

According to the District Health Barometer, at the end of March 2013, approximately 2.1 million (33% up from 1.4 million in 2012) adults and 148,000 children under the age of 15 were receiving ART. Of the adults, more than 700,000 were in the five high burden districts of eThekwini, Johannesburg, Ekurhuleni, Tshwane and Ehlanzeni2.

The report acknowledges that these indicators do not give clear indications of enrolment, coverage or adherence. It also acknowledges the potential for overestimation of retention in care, as it depends on reporting of patient outcomes (such as deaths and losses to follow-up) by health facilities, which is often incomplete.

Optimistic estimates, mostly from research cohorts, tells us that approximately 1 in 5 patients has left the programme (i.e. is lost to follow-up) three years after starting ART3,4. Data on the proportion of patients lost to follow up in South Africa’s ART programme is not publicly available to date.

And maybe most importantly, we don’t know how many of the patients currently on ART have an undetectable viral load, the ultimate sign of treatment success. With a detectable viral load, patients not only deteriorate immunologically and clinically, but also develop drug resistance and have a higher risk of transmitting HIV to others.

An analysis of five South African public sector programmes with research support estimated that between 15% and 19% of patients were failing first line ART at five years on treatment5. This might be an underestimate given that at least one district up to 50% of patients on ART were found to have a detectable viral load in 2012.6

Again, no national data on virological outcomes is publicly available at the moment.

**WHY SHOULD WE BE CONCERNED ABOUT RETENTION IN CARE?**

Quoted figures on retention in care in South Africa often compare unfavorably with those of its less resourced neighbors. In a systematic review among Southern African HIV programmes overall retention was found to be 76.8% at 12 months, with 5 of the 7 South African sites included having lower retention than this. In addition, trends of retention over time often appear to be falling year on year.

Earlier initiation leads to lower mortality, thus we would expect retention in care to improve, yet we now declining retention due to increasing losses to follow-up. Whilst we would hope for programmes to gradually better serve the needs of patients as they mature, the reality seems to be that programmes are struggling to adapt to increasing patient burden. Quality goes down as quantity goes up. The reality might be even bleaker if we consider that programmes that do well may be likely to publish their results.

**IS THE DATA TO BLAME?**

Conventionally we have looked at the patient path from diagnosis to retention on treatment as a straight path along which patients walk, with those walking off into the land of loss to follow up never to be seen again. The reality is more likely to be a maze where some patients do follow this linear journey, for many a multitude of psychological and social factors give rise to an erratic and unpredictable engagement and disengagement with multiple service providers in one or more locations over time, basically walking on and off the path.

Linear cohort monitoring systems were not designed to deal with such complexity, and although they may do so at a stretch, in many cases such patients will be lost to one system or counted as a new patient on their return, resulting in an overestimation of loss to follow up.

A second reason why systems may overestimate loss to follow up can be found in the pharmacy. Frequently many more patient supplies of drugs are dispensed in a clinic’s pharmacy than there are patients in the system. While a first reaction to remove that confusion or pharmacy errors are to blame, in many cases when we look in detail we find another explanation. Many patients simply get their drugs after no, or minimal contact with a nurse. This can result in their records never being recorded in the clinic’s data system.

The issues above will lead to an underestimation of patient numbers, but problems with data may also overestimate retention. Most importantly, without proper systems to remove those deemed to be lost to follow-up from the cohort of actively followed patients, estimates of active patients in clinics without the more advanced computer systems may be closer in reality to estimates of all the patients who ever started ART in that facility. Perhaps this may even explain why some well-resourced programmes do not show greatly improved results (or even worse ones) than poorly resourced ones. They may just be better at counting their patients as lost.

It would be a mistake for us to look at the often disappointing data on retention in care in South Africa as “just a data problem” though. While the gaps in the data mean that we can’t be sure what is going on, we do have enough information to make some educated guesses, and to begin to address issues identified.

**WHY MY RETENTION IN CARE OF PATIENTS ON ART BE FALLING?**

Firstly, the health systems’ incapacity in the face of massive scale up of patients on ART. The addition of more than two million people on antiretroviral treatment in the South African public health system in the past few years is a public health intervention of unprecedented scale in history. This hasn’t been matched by equivalent increases in human and structural resources. The system has reached the limits of its capacity in its current form, it needs to transform.

The observation that rapidly growing programmes can have particularly rapid declines in retention gives some support to this hypothesis. Pinpointing the principal limiting resource needs is challenging, but given the key role of counseling in promoting adherence and the time consuming nature of the activity, attention here is warranted.

In addition, with more patients starting ART earlier, fewer will have experienced severe disease. Without ever having such experience we can wonder whether the motivation to remain disease free and in care can be as strong.

Finally patient fatigue may be setting in. Some patients have spent a decade or more taking their ARVs, a decade of the often monthly trudge to the frequently overcrowded clinic, of queues and sometimes side effects. It might not be unexpected if some were to lose sight of the life saving power of these drugs.

**SUMMARY**

In summary, the achievements of the South African antiretroviral programme are undeniable, yet much remains to be done in terms of monitoring its progress. Current numbers on treatment are not representative of the population, and national data on loss to follow-up and treatment failure are not publicly available. To improve outcomes, the health system has to adapt to patients’ needs and numbers. This will require a shift towards more community focused models of care. We can and should know better, but we can’t afford to wait before we start doing better.

Making better use of numbers

Prof Francois Venter and Prof Helen Rees, WITS Reproductive Health & HIV Institute

The Minister of Health and other senior health officials are rightly proud of the recent good news about HIV in South Africa: the rate of new infections is dropping, the number of people tested for HIV is close to 20-million (since 2010), and around 2.1 million people are now on antiretroviral therapy (ART).

But how can we build upon these achievements and how can we measure the success of our existing programmes? We need to use existing markers to monitor progress more effectively. To do this, independent monitoring of clinic and district information systems must be implemented so that programme performance can be objectively verified. At the Wits Reproductive Health & HIV Institute (Wits RHI), we feel that the National Health Laboratory Services (NHLS) is well-placed to perform a key oversight role in the health sector.

The NHLS has an extensive national footprint and relatively sophisticated data systems and is therefore ideally placed to provide more accurate sources of data. With the National Department of Health’s (DoH’s) decision to implement a ‘single patient identifier’ across the health system, it will be possible to track individual level data through the health system. The NHLS is able to track laboratory requests right down to a facility level, and could therefore provide invaluable reporting at all levels of the health system. Certainly, these data will be more reliable than data through the health system. The NHLS is able to track laboratory requests right down to a facility level, and could therefore provide invaluable reporting at all levels of the health system. The NHLS is a national asset. Few other countries have such well-integrated laboratory services in the state sector.

Viral load data from the NHLS could be used in a similar way. The testing of viral loads is only undertaken when a patient is on ART and, according to the new guidelines, this is done annually after the first 6 months. Mapping how many viral loads have been measured in an area can provide us with a rough idea of the number of people on ART, the level of adherence (people taking their medication will be ‘undetectable’, so the overall proportion will be a quality measure), and the level of retention in an HIV programme. This again should correlate roughly with the number of patients on treatment. When triangulating these data with health registries and pharmaceutical deliveries, this data could help at a provincial, district and sub-district level, with issues such as M&E improvements, and identifying misreporting and procurement corruption.

We believe that the National Minister of Health should use the CD4 data available from the NHLS to gain a better understanding of the progress of HIV programmes in South Africa. Mapping the data onto district maps and charting the number of CD4 tests done would provide useful information: new patients who have received a CD4 count would probably have been recently tested, and this therefore will give us a rough idea of the amount of testing being done. The levels of immunosuppression, that is the average CD4 count at initiation, recorded allow us to determine how effective the testing processes are, and whether linkage to care is being done. Any district with an initiation CD4 threshold level of over 200, for example, is probably doing sufficient testing, and is effectively linking their patients to care. But clinics reporting low CD4 counts, could either be assumed to not be testing enough people or not linking them to care.

“With the National Department of Health’s decision to implement a ‘single patient identifier’ across the health system, it will be possible to track individual level data through the health system.”
Taking stock of HIV response

Dr Quarraisha Abdool Karim, Associate Scientific Director CAPRISA

The National Strategic Plan is a dynamic document that needs to be adapted through regular reviews of the evolving HIV epidemic, emergence of new knowledge on factors contributing to the epidemic or HIV prevention and treatment and impact of programmes being implemented. Monitoring of activities that are outlined in the NSP is as important as evaluating the impact of these activities on the goals of reducing transmission of HIV, morbidity and mortality rates and reducing stigma and discrimination.

The South African National AIDS Council (SANAC) remains a key structure to play this role. The rapidity with which the new secretariat is able to be fully functional and operational will determine how effective it can be in fulfilling this role as a country co-ordinating mechanism and maximising cooperation between all sectors within and outside government.

On the global science front, we have seen that biomedical advances on vertical transmission and treatment have substantially reduced HIV infection in infants and transformed AIDS from an inevitably fatal condition to one that is a chronic, manageable one. Scientific advances, centrally around the use of ARVs to reduce vertical transmission, treat infants and adults and prevent HIV infection has injected new hope that the epidemic can be controlled reflected in optimistic talk of an AIDS-free generation, and the 3 zeros (0 new infections, 0 deaths and zero stigma and discrimination).

An urgent and important task is to determine the role of PrEP (pre-exposure prophylaxis) and TasP (treatment as prevention) for South Africa and map out what the critical next steps are for programming. Are there niche populations for TasP eg sex workers, truck drivers and migrant workers and for PrEP and who are they? In the meantime research efforts to find an effective microbicide, vaccine and cure continue.

As a country how are we doing implementing what we know works? The most robust data we have come from the Department of Health. Data from the rural district of Hlabisa, one of three highest burden HIV districts in the country demonstrate that a modest 30-40% coverage of HIV infected individuals being initiated on ART treatment based on CD4 treatment guidelines of CD4 counts <200 has resulted in an 11 year increase in life expectancy in this community. Overall, while good progress is being made on reducing vertical transmission and treatment access; preventing HIV infection remains a major challenge. In terms of vertical transmission infant drug formulations and reducing HIV transmission through breastfeeding remain a challenge.

So why are we not seeing the kind of impact on the HIV epidemic that we would like to see? There are at least four factors contributing to this: 1. age-sex difference in HIV infection with young women a key driver of the epidemic and lack of availability of women initiated prevention technologies; 2. weak health care delivery systems unable to achieve coverage rates of needed interventions or introduce new interventions; 3. stigma and discrimination; and 4. gender-power dynamics that underlie the vulnerability of those who bear the brunt of the burden of HIV.

A key and unique feature of the HIV epidemic in South Africa is the age-sex difference in HIV acquisition patterns. Young women acquire HIV infection about 5-7 years earlier than men. Young women in the 15-19 year age group have about 4-6 fold higher rates of HIV infection than their male peers. Inter-generational sexual coupling patterns with young women aged 15-19 years with males in their mid twenties and older is a key driver of the epidemic and our failure to prevent HIV infection in young women equals our failure to control the epidemic. Preventing HIV infection in young women under 20 years is key to altering our current epidemic trajectories.

There is some evidence showing that women who complete 12 years of schooling have a seven fold reduced risk of HIV acquisition compared to those who abandon their schooling earlier. Gender based violence is also associated with higher HIV acquisition rates. High teenage pregnancy and rates of other sexually transmitted infections highlight that HIV prevention efforts in young women have to meet their sexual and reproductive health needs. A key obstacle to prevention and care efforts remain stigma and discrimination. AIDS related stigma and discrimination compounded with other forms of stigma and discrimination such as those based on sexual orientation, moral and judgmental attitudes with respect to age of sex debut, gender and recreational drug use. It creates a vicious cycle of silence, ignorance, fear, and denial or personalisation of HIV risk. It is a key reason why we continue to see people dying of AIDS, up to 500 000 in 2011 alone.

Window of opportunity

Our understanding of the HIV/AIDS epidemic, the collective body of knowledge on prevention and treatment and political and budgetary commitment provides a unique window of opportunity to South Africa to alter current epidemic trajectories for local and global benefit. This confluence of factors enables us to effect a paradigm shift in our response. Within this context, what are some of the key considerations for smarter and more effective implementation?

Prioritise high HIV burden districts and key populations. Although South Africa has a generalized epidemic there is a diversity of dynamic epidemics within and between provinces. We need to shift from doing a little for everyone to focusing on geographical hotspots (districts in the country bearing a disproportionately high burden of HIV infection) or key populations driving the epidemic.

Intensify a customised comprehensive effort in these hotspot communities and populations based on a nuanced understanding of key factors contributing to the epidemic in that community. Move away from a cookie cutter or magic bullet approach to a more customized set of evidence based activities responsive to the local epidemic.

Strengthening of health care delivery systems. Sufficient and adequate infrastructure and resources and structural improvements are urgently needed to create a seamless integrated facilities. Of particular important is ensuring good infection control to minimise health care facilities becoming a source of infection especially TB. Ongoing training and support of health care workers to rapidly incorporate the policy changes that are required to make an impact on health outcomes and ensure a growing cadre of well-trained health care workers.

A more concerted and focused effort to reduce HIV infection in young women.

“...systems and procedures to undertake what needs to be done. Strengthening of supply chain systems to minimise treatment interruptions and ensure comprehensive service delivery. Health information systems that enable and inform decision making at the coalface. A more concerted and focused effort to reduce HIV infection in young women. For young men and women adolescent friendly SRH services and treatment services that can be accessed at health care facilities and in school. Knowledge is a pre-requisite and the existing life orientation school based programmes should be expanded to integrate SRH information into HIV prevention efforts. At a school and community level a norms that eliminate inter-generational sexual and substance abuse, eliminate gender based violence, teenage pregnancies and foster high school completion rates can make a difference as we await biomedical advances. At an individual level interventions that support internalisation of HIV risk, how to overcome peer pressure and create confidence in the future could complement the community efforts. Simple interventions in schools to separate out adult from child learners, reduce overcrowding in classrooms, support school completion rates for female learners, social services to learners from vulnerable/child headed households are immediate things that can be done...”
The Chronic Crisis

On 10 October 2012, staff at Mthatha depot in the Eastern Cape staged a strike, leaving the depot with only 10 out of more than 40 working employees. Coupled with chronic supply chain issues this precipitated widespread medicine stock-outs in the region. An estimated 53% of facilities served by the depot experienced ARV and/or TB medicine stock-outs and 24% sent patients home without any antiretrovirals.

In December 2012 MSF & TAC responded to the crisis by supporting staffing, management and medicine delivery at the depot. As part of a wider civil society collective, which included the Southern African HIV Clinician’s Society, SECTION27, Treatment Action Campaign (TAC), Rural Health Advocacy Project (RHAP), Rural Doctor’s Association of Southern Africa (RUDASA) and Médecins Sans Frontières (MSF), these finding were published in a report, with the objective to effect positive changes in the provincial supply system.

Returning to the area in May 2013 to evaluate progress,

Inaction puts thousands of patients’ lives at risk

Monique Lines, Gilles Van Cutsem, Amir Shroufi and Bella Hwang, Stop the Stock-outs Project

Drug stock-outs are serious. In people living with HIV, TB or other serious diseases it could mean death. A survey by Stop the Stock-outs has revealed a poor state of affairs in several provinces. But let’s go to Mthatha where matters first came to a head.

The map above shows health facilities reporting a stock-out or shortage of ARV or TB supplies in the past three months. Each red dot represents a facility with a stock-out or shortage.

Map data: Google, AfriGIS(PTY) LTD, myHeatmap.com

Drug stock-outs are serious. In people living with HIV, TB or other serious diseases it could mean death. A survey by Stop the Stock-outs has revealed a poor state of affairs in several provinces. But let’s go to Mthatha where matters first came to a head.

The Chronic Crisis

On 10 October 2012, staff at Mthatha depot in the Eastern Cape staged a strike, leaving the depot with only 10 out of more than 40 working employees. Coupled with chronic supply chain issues this precipitated widespread medicine stock-outs in the region. An estimated 53% of facilities served by the depot experienced ARV and/or TB medicine stock-outs and 24% sent patients home without any antiretrovirals.

In December 2012 MSF & TAC responded to the crisis by supporting staffing, management and medicine delivery at the depot. As part of a wider civil society collective, which included the Southern African HIV Clinician’s Society, SECTION27, Treatment Action Campaign (TAC), Rural Health Advocacy Project (RHAP), Rural Doctor’s Association of Southern Africa (RUDASA) and Médecins Sans Frontières (MSF), these finding were published in a report, with the objective to effect positive changes in the provincial supply system.

RETURNING to the area in May 2013 to evaluate progress,

I am a patient at a clinic in Tzaneen and have been on ARVs since 2005. I went to the clinic this year and was given only 2 weeks supply and told to come back when finished. When I went back at the end of 2 weeks, I was told that the drugs were out of stock and I went for 2 weeks without treatment. At present, I have found out that my CD4 count has decreased from 1000 to 500. Five people from my support group have died in the past year due to resistance. I am scared of developing resistance.” Patient Interview October 2013
**Stock-outs continued**

we were surprised and saddened to find that 40% of facilities contacted continue to experience on-going or intermittent stock-outs of ART and/or TB medicines.

To better understand why stock-outs were occurring we contacted patients and health care staff over the country and quickly realised that stock-outs were occurring across every province. What this means is unnecessary death, sickness and medicine resistance. As painfully illustrated by patient testimonies, the most vulnerable are the most at risk and the least able to advocate their own case.

This brings us to where we are now, reporting the results of a national survey of medicine stock-outs completed during the months of September and October 2013. This is a survey conducted by the civil society consortium mentioned above, in response to the failures of ART and TB medicine supply witnessed. In Africa’s wealthiest nation, in the world’s largest HIV programme, this situation must end. The system must become accountable to the patients it serves.

**How did we investigate the extent of stock-outs in South Africa?**

To measure the extent and impact of HIV and TB stock-outs we set out to call by telephone as many clinics as we could, to ask them directly about what they were seeing and doing. A stock shortage was defined as less stock of a medicine available than required for projected usage until next order received (as identified by the health care worker responding). A stock-out was defined as physically having no stock on shelf or in facility when required for patient use.

Of all the facilities in the country we identified, we were able to contact 61% (2432 facilities out of 3827). The median length of stock-out or shortage of ART or TB supply reported was 30 days (inter-quartile range: 14–60 days) with a minimum of 1 day to a maximum of more than 165 days. Most often facilities reported relying on a depot for delivery (one in two facilities); one in three relied on a hospital, one in ten on a sub-depot, one in thirty on alternative facilities and one in three hundred on direct supply.

**Impact of stock ruptures on patients**

Health care workers in facilities were asked about the impact of stock-outs or shortages on their patients. We have divided their responses, for simplicity, into high impact (if the patients were sent home without medication or referred elsewhere without medication), medium impact (regimen changes or if patients were given less than their full supply) and low impact (the facility borrowing to meet patient need or the patient given an alternative pack size).

The breakdown of patient impact can be seen in the pie chart below.

**ARV and TB Supply**

Stock-outs and shortages were reported more often for ARVs than for TB medicine. Only one in thirty facilities reported a problem with TB medicine. North West reported the lowest number of facilities with problems (one in two-hundred) and Limpopo the highest (one in fifteen). Problems with ARV supply were much more frequent, with one in four facilities nationwide reporting stock-outs or shortages in the past 3 months. Western Cape reported the least (one in forty) while Free State had an alarmingly high level of stock-outs and shortages (more than 50% of facilities). Lamivudine and Efavirenz were the two medicines most often facing a stock-out or shortage of.

**Discussion**

This national survey uncovered alarmingly high numbers of stock-outs and shortages of ARVs and TB drugs. Supply issues need to be urgently addressed so that no patient leaves a health facility without their life saving medicines.

The survey does not allow pinpointing of the failures in the supply chain that have led to stock-outs. It is now evident that focused interventions at all levels of the complex health system are essential to improve patient access to medication. Yet there are some key focus areas that need urgent attention, including, but not limited to, the following:

- **Stock-outs and medication shortages are underreported and monitoring systems must improve.**
- **The first step in solving the problem is acknowledging that it exists.**
- **Poor visibility of stockouts leads to lack of accountability and delayed responses.**
- **A number of health professionals reported that primary health care staff often lack adequate training to manage medication supply.**
- **Staff at facility level also needs to be trained on strategies to ensure minimal harm to patients if a stock item is not available.**

**Stopping stock-outs will take concerted effort**

We call upon the National Department of Health to appoint a national task force to investigate and address the issue of stock-outs.

Each individual Provincial Department of Health needs to work in collaboration with the National Department in order to stop stock-outs. This will require an agreed clear strategy, with pre-defined targets and timelines to be followed.

**To report stock outs to the SSP, send a SMS or “Please Call Me” to 084 855 7867 or email report@stockouts.co.za**

**Civil society has an important role in helping to bring stock-outs to an end**

The Stop Stock-outs Project (SSP) is civil society’s response to bring transparency to medicine problems facing patients. The main goal of the SSP is to bring awareness to stock-outs as they occur and highlight problems areas in the supply chain that need attention. The project aims to empower the tens of thousands of patients and clinicians affected by stock-outs. It is time to stop stock-outs. The system must be accountable to those it serves and an appropriate response from all levels of the health system is required.

Given the magnitude of the identified challenges in the Free State and Limpopo, as well as individual districts with exceptionally high levels of stock-outs, emergency joint action, from both provincial and national departments of health is needed immediately. Failure to do so has the potential to cause unnecessary suffering and death. The National Strategic Plan lays out achievable goals and an admirable vision for the health service in South Africa. If we are to achieve this vision, then ongoing problems concerning medication stock-outs cannot be ignored.

However, solutions are available. Not least making the system more accountable to the people it serves: the patients.

---

**Mthatha Pharmaceutical Depot, January 2013.**

NSP Review #9 2013

21
Palliative care is mentioned only once in the National Strategic Plan, within a sub-objective indicating a commitment to keeping people with HIV, STIs and TB within the healthcare system and adherent to treatment. There is, however, no recognition of the fact that that some people living with HIV will experience declining health that will lead to death, or that the mortality rate for people with HIV remains high, especially if they are co-infected with TB.

Although the plan recognises the importance of providing care and support, thus far it has not included specific indicators for such interventions. The Hospice Palliative Care Association (HPCA) believes that a comprehensive response to healthcare needs must include such indicators and is campaigning for their inclusion in the NSP. If the plan does not make reporting compulsory, there is a risk that such interventions will be regarded as less important. They may also be neglected within the competing demands of the health system.

The NSP refers frequently to the importance of providing comprehensive care and support, but we argue that it has failed to recognise how individuals experience living with HIV and TB. Many patients are faced with distressing symptoms as well as emotional and existential anxiety. It is therefore important that personal challenges are addressed in public health planning. The HPCA recommends that specific care and support indicators be included in the NSP: 1) pain assessment and management, 2) referral to community-based care and support services, and 3) an annual audit on the quality of care support.

The first of these indicators – pain assessment and management – is vital because pain is one of the most debilitating and distressing symptoms encountered by many patients with chronic illnesses, including HIV. Studies of patients on highly active antiretroviral therapy (HAART), for example, have shown that between 31% and 74% experience pain, and this can interfere with normal functioning and daily life. A study of indicators to measure pain management in patients with HIV (conducted by the University of Cape Town and commissioned by UK Consortium on AIDS and TB. Many patients are faced with distressing symptoms as well as emotional and existential anxiety. It is therefore important that personal challenges are addressed in public health planning. The HPCA recommends that specific care and support indicators be included in the NSP: 1) pain assessment and management, 2) referral to community-based care and support services, and 3) an annual audit on the quality of care support.

The first of these indicators – pain assessment and management – is vital because pain is one of the most debilitating and distressing symptoms encountered by many patients with chronic illnesses, including HIV. Studies of patients on highly active antiretroviral therapy (HAART), for example, have shown that between 31% and 74% experience pain, and this can interfere with normal functioning and daily life. A study of indicators to measure pain management in patients with HIV (conducted by the University of Cape Town and commissioned by UK Consortium on AIDS and International Development) has suggested that the prescription of analgesics could be a useful workable indicator of care.

The second indicator we would like to see included in the NSP is the referral of patients to community-based care and support programmes. This too is a simple way to monitor and measure care and will help to ensure that HIV patients receive continuity of care. The monitoring of support will also be possible at a household level.

Recent research has shown that a worrying number of people are still lost to treatment, even when they receive good facility-based HIV care. Providing support at the household level, as studies have shown, can help to improve levels of retention in care. Recognising the importance of this, one of the objectives of a new HPCA project – the Care and Support for Improved Patient Outcomes (CaSiPO) – is to integrate comprehensive palliative care and support into government initiatives. Doing so will enable us to work together with government and civil society partners to create a more integrated referral and retention system. The project aims to ensure that patients are enrolled into care and treatment programmes following their HIV diagnosis and given access to a continuum of high quality Comprehensive Care and Support – Palliative Care (CCS PC) services.

Maintaining optimal health and improving quality of life are important palliative care goals, even when patients are living with chronic illnesses. Palliative care is provided in conjunction with active treatment such as HAART, TB treatment. Palliative care also provides symptomatic treatment to address distressing symptoms and comfort care at the end of life, while working towards the goal of zero deaths. The NSP should clearly acknowledge the current reality of HIV mortality and make provision for end of life palliative care. While Intervention 3.2.1 of the NSP refers to the “appropriate referral for side effects or specific needs, including palliative care”; the commitment to such services needs to be more explicitly stated.

It is important that people experiencing progressive illnesses also receive good quality care and that they are not abandoned by South Africa’s healthcare system. An audit of quality of care using internationally-validated measures is the key valuable indicator that we believe should be included in the NSP. Doing so will help the government to improve the quality of the healthcare support it provides.

No NSP indicators to help patients in pain

Liz Gwyther, Hospice and Palliative Care Association of South Africa

HIV: Not enough attention given to children

Joan van Niekerk, Yezingane Network and Childline South Africa

Children constitute about 40% of South Africa’s population and it is therefore critical that the National Strategic Plan (NSP) for the Prevention and Management of HIV, STIs and TB, focuses on the needs of this large and vulnerable group.

In the midterm review of the 2007-2011 NSP the Yezingane Network (a civil society network of organisations working to address the impact of HIV and AIDS on children), noted that the first NSP lacked specific indicators for the management and prevention of the HIV pandemic among children.

At a workshop in 2008, the Network therefore proposed the development of a list of indicators to address this weakness, as well as an indicator scorecard for children living with HIV and AIDS. A scorecard of well-defined, child-oriented indicators, it argued, would enable the collection of qualitative and quantitative information specific to measuring the pandemic’s effects on children. Each of the ten indicators, chosen in consultation with technical experts, was also intended to provide critical information on the extent to which South Africa had met its obligations to children in accordance with the NSP’s objectives. Measuring these indicators annually, the Network suggested, would help to:

- focus attention on children in the national HIV/AIDS agenda
- monitor success in addressing the impacts of HIV and AIDS and the NSP on children
- highlight gaps in the information we need in order to monitor progress, and
- provide an advocacy tool for addressing service and data gaps.

The scorecard was launched in August 2009, but the impetus behind this first initiative slowed in the later years of the 2007-2011 NSP. During the development of the second plan (2012-2016), indicators relating to the success of the NSP in relation to children were, once again, not given adequate attention. The core indicators of the new NSP, and some of the specific indicators that relate to the NSP’s first three Strategic Objectives, do address issues related to the well-being of children. However, there is a need to extend the scope of these indicators so that they relate more explicitly to the needs of children - and even to develop indicators that are specific to children. This way, we will be able to measure more precisely the impact the NSP is having on this vulnerable group.

As yet, no specific indicators have been developed for the fourth strategic pillar of the NSP which relates to ensuring the protection of human rights and greater access to justice. This is of particular concern given that the needs of children require particularly careful tracking in relation to these issues. The protection of children’s rights is dependent on adults, and the access children have to justice may therefore be facilitated or blocked by the adults in their world.

Children are vulnerable to HIV infection through sexual abuse and neglect. Without child-specific indicators to measure the protection of their rights, it will remain difficult to measure the progress we are making in improving their access to justice.

Specific measures that could be implemented to help protect the rights of children include the clear disaggregation of ages in police statistics so that it is clear how many children are affected (by crime). The measurement of compliance with ARV regimens following sexual assault is also important. The outcomes for children who are victims of crime and who are dealt with by the criminal justice system also need to be tracked. Many children remain insufficiently supported by the legal system, especially when cases involving children are withdrawn from court.

Although the NSP addresses the issue of stigma with regard to discrimination in the workplace and access to services, the plan fails to consider this issue more widely in relation to children and their experiences of prejudice at schools. It is important that children who are affected by the pandemic, or who are HIV positive, are helped to cope with social stigma or negative responses. Childhood is a time during which social skills are developed and these are strongly shaped by interactions with other children and adults. Adverse social experiences during childhood may have a profound impact on adult functioning. It is therefore particularly important that we protect children from alienation and social exclusion. Further meaningful indicators must be developed to ensure that the NSP also succeeds in addressing the health needs of children. The midterm review of the NSP should be used as an opportunity to do so.
It is critical that the success of the National Strategic Plan is also measured against its response to children.

There are a number of critical areas that need to be examined more closely when it comes to children. The summary points below capture some of the areas that need special and urgent attention.

- **PREVENTION OF MOTHER-TO-CHILD TRANSMISSION (PMTCT)**
  - New treatment drug regimens are now adopted for PMTCT. Currently regimens are Option B (triple antiretroviral therapy for all pregnant women until breastfeeding is complete) and in the Western Cape, Option B+ (immediate continuous antiretroviral therapy from pregnancy).
  - Researchers caution that there is poor ART adherence in pregnancy and this is confirmed by data from several African countries.
  - For infants, undiagnosed HIV in the mother reflects the greatest risk of vertical HIV transmission at birth. In addition to a diagnostic PCR test at six weeks of age, more attention should be given if pregnant women have received sub-optimal treatment because they report to the clinic very late (beyond 20 weeks gestation) or if they missed any clinic appointments. Current polymerase chain reaction (PCR) testing at six weeks mainly identifies perinatal transmission – the HIV transmission that happens before or during birth. It is important for doctors to use their discretion and conduct these PCR tests at an earlier stage if some of the risk factors on the side of the mother are present.
  - With efavirenz part of the ART regimen for PMTCT, it is essential that data on perinatal transmission (PMTCT) is recorded. All babies should be identified as HIV-exposed at the time of their first PCR test at six weeks of age. Similarly, growth data for tenofovir-exposed infants should be collected until at least two years of age.

- **INFANT FEEDING**
  - More information on maternal feeding choices should be collected now that replacement milks (formula) are no longer subsidised by the State. How many mothers elect formula feeding despite the evidence of a subsidy? How many mothers undertake exclusive breastfeeding for the first six months of life and how many revert to mixed feeding? Also, how many babies are infected because of feeding practices? It is a labour intensive exercise to collect this data, but we need to do it.

- **ART IN INFANTS**
  - Age of initiation is key to a good outcome. Research has shown that it is critical to initiate treatment as soon as the baby is diagnosed. Currently, the data only indicates whether the baby was initiated on treatment in the first year of life. In order to monitor whether the system is in fact diagnosing infants early, it would make sense to record their actual age when started on treatment for example at six weeks or three months.

  - This will help to establish where in the system improvements are required.

- **PLASMA HIV RNA (VIRAL LOADS)**
  - Data, which includes the actual viral load of the infants, should be collected per district and per year and reported by age group and sex.
  - Those patients who are part of the PMTCT programme and adolescents should be special focus areas.

- **2ND AND 3RD LINE ART**
  - Data on numbers of patients on this regimen or in need of this regimen should be collected for planning access to resistance testing.

- **ADOLESCENTS (10 TO 18 YEARS OF AGE)**
  - The transitioning of adolescents into adult services should be monitored. The number of HIV-positive adolescents, distinguishing between those who are perinatal survivors (infected at birth or via breastfeeding) and through sexual acquisition, should be reported and monitored by age. Outcomes for those entering and exiting the adolescent period should be reported. Thereafter, in adult programs, both perinatal survivors and those who acquired HIV sexually should have outcomes reported separately to other adult clinic attendees.

- **SUPPORT SERVICE FOR ADHERENCE**
  - This should be measured and reported in children. We should also report on the availability of dedicated social workers and psychologists for ARV and TB programs. Poor adherence is often a symptom of complex issues in patients’ lives.

- **SIMPLIFICATION OF REGIMEN**
  - Fixed-dose combinations (FDC) reduce cost and simplify administration of ART. The availability for children should be documented as South Africa probably has the lowest FDC usages for children on the continent.
Analysing the Drivers of Non-adherence Among 15-Year Old Adolescents in Nkhome District, Zimbabwe

Non-adherence to antiretroviral therapy (ART) remains a major problem, particularly among young people, and is associated with poor health outcomes and increased transmission of HIV. In Nkhome District, Zimbabwe, a study was conducted to assess the drivers of non-adherence among 15-year-old adolescents. The findings revealed that adolescents face multiple challenges, including financial constraints, long journey times to clinics, and the need for continuous support.

The study also highlighted the importance of early identification of non-adherence and the need for targeted interventions. It recommended the implementation of strategies such as providing mental health services, strengthening health services to offer child- and adolescent-friendly HIV and TB services, and ensuring effective management interventions.

Dr. Paul Roux and Dr. Phindile Gumede from the University of Cape Town and Groote Schuur Hospital conducted the study. The findings support the need for comprehensive programmes to improve adherence and reduce the impact of HIV among adolescents.
Class of 2013

Mary-Jane Matsoalo, Treatment Action Campaign

Treatment Action Campaign activists have scored the Health MECs in their provinces based on their engagement with civil society, their participation in the AIDS Councils and their approach to the most pressing challenges in their provinces. More specifically, the MECs were scored on their response to issues related to HIV. Health minister Dr Aaron Motsoaledi’s performance was also evaluated.

A

MINISTER
Dr Aaron Motsoaledi
Start date: May 2009

Positives: Minister Motsoaledi is energetic and determined to solve the health system’s deep systemic problems. Reacting quickly to crises such as drug stock-outs and high death rates at hospitals, he has overseen the rapid expansion of South Africa’s HIV programme following the long period of government denialism.

Motsoaledi has a ten point plan to improve healthcare services in South Africa. If he is successful, the plan will go a long way to solving issues such as high maternal and infant mortality rates. Motsoaledi faces significant challenges in getting the provinces to work harder at implementation and to be as committed as he is. He must get them to focus more on improving the lives of those relying on the public sector.

Negatives: Minister Motsoaledi has far too much on his plate. With only a small team of competent managers to support him, he risks becoming burnt out. He needs more help.

Civil society: From his first day in the post, the Minister has worked closely with members of civil society and is not scared to ask for advice. His mobile number is widely known.

SANAC: Motsoaledi has not yet managed to transform this institution. SANAC risks becoming an organisation unable to turn ideas into actions. It is still failing to drive the National Strategic Plan.

Report summary: Motsoaledi is one of the best Health Ministers South Africa has had. We hope he retains his post after the 2014 elections.

B

Doing a good job and must remain in 2014

C

Could have received an A score, but there are some challenges

D

Average performance with room for improvement

E

Not a good performance in 2013, could go either way

F

Heading for a fail

G

Fail and must be fired

KWAZULU-NATAL
Dr Sibongiseni Dhlomo
Start date: April 2009

Positives: Access to antiretroviral therapy (ART) in the province is good. Dhlomo has a hands-on approach to issues such as preventing fraudsters or unsafe medical practices. He is not afraid of asking for public assistance when trying to resolve difficult problems such as the high rate of maternal mortality in the province.

Negatives: Is not prepared to tackle the Tara Klamp issue (www.tac.org.za). He has failed to establish consultative civil forums in accordance with the National Health Act. Dhlomo reportedly also behaved inappropriately by allegedly using an emergency helicopter to attend a private wedding. He has never explained himself and has never been held to account.

Provincial AIDS Council: He is active in the Council and has played an important role in making it a critical platform to tackle HIV issues in the province. KwaZulu-Natal is held up as a best practice model when it comes to AIDS Councils.

Report summary: A person who can be stubborn, but who has the potential to become an excellent MEC.

GAUTENG
Hope Papo
Start date: July 2012

Positives: Papo is attempting to implement a turnaround strategy for Gauteng that includes the improvement of services at hospitals, the replacement of old equipment, and the employment of new CEOs at hospitals such as George Mukhari and Chris Haní Baragwanath.

Negatives: Papo’s response to drug stock-outs in Gauteng has been poor and he denies the seriousness of the problems.

Civil society: Papo does not engage well with members of civil society. He has only met once with TAC in 2012 when the organisation reported unacceptable hospital conditions. Papo has sent other officials to follow-up meetings.

Provincial AIDS Council: He attends some meetings but usually the Director General represents him.

Report summary: Very few people have managed to meet with Papo. He appears infrequently and usually only following pressure or protest. Communities are seldom informed in advance about his clinic visits. However, TAC branch members are vigilant. If they spot him, they use the opportunity to engage him.

EASTERN CAPE
Sicelo Gqobana
Start date: November 2010

Positives: None

Negatives: Sicelo Gqobana is a teacher without a medical background and this could explain why he appears to be out of his depth in this portfolio. He has failed to tackle the corruption in the health system and offers neither clear direction nor leadership. Instead, he is accused of removing officials who have attempted to address this issue.

Gqobana failed to intervene in the strike at the Mhathha drug depot or to address the shocking state of the Village Clinic in Lusikisi. The national Minister of Health intervened instead.

On his watch, many healthcare workers in rural areas have continued to live in unacceptable conditions, without electricity, transport or running water. People are deployed to positions for which they are not qualified, and fraudulent payments to non-existent ‘ghost workers’ are continuing. Gqobana refuses to respond to communication from residents or members of civil society. Many hospital and clinic buildings are falling apart.

Civil society: His engagement is extremely poor. TAC has been trying to meet with him since 2012. Gqobana uses public platforms to attack those who hold him to account.

Provincial AIDS Council: Gqobana has not attended Council meetings.

Report summary: Gqobana refuses to acknowledge the scale of the crisis in the Eastern Cape. We recommend that he be removed from his post.

NORTHERN CAPE
Mxolisi Sokatsha
Start date: May 2009

Positives: The Provincial AIDS Council is now functional. Sokatsha permitted civil society members to co-chair the council in his absence. New clinics have been built and funds have been made available for a People with AIDS (PWA) summit.

Negatives: Many rural areas still do not have clinics. Communities depend on mobile clinic services but these are unreliable. Sokatsha needs to provide more bursaries for students who want to study health.

Civil society: TAC does not have a branch in the province but the MEC works closely with the National Association of People living with HIV/AIDS (NAPWA).

Provincial AIDS Council: Sokatsha is an active member of the Provincial AIDS Council and activists are able to contact him easily.

Report summary: Sokatsha is flexible, supportive and approachable. Activists regard him as being only an SMS away.
Class of 2013 continued

**WESTERN CAPE**

**Theuns Botha**

Start date: April 2011

**Positives:** Theuns Botha facilitated the building of the Mitchells Plain and Khayelitsha Hospitals.

**Negatives:** He has failed to address the issue of poor service at Khayelitsha Hospital, despite being aware of problems at the facility after TAC sent a memorandum in September 2013. TAC has informed him that the service at the Mitchell’s Clinic is also poor and that patients are forced to travel to Khayelitsha Hospital for treatment. We feel his response has not been satisfactory and that he does not address our concerns in his letter.

**Civil society:** Poor engagement.

**Provincial AIDS Council:** The MEC chairs the Provincial AIDS Council.

**Meetings:** Botha has met with TAC on a few occasions but has appeared defensive.

**Report summary:** Theuns Botha seems to respond poorly to concerns. His defensive reactions suggest that he believes TAC is politically aligned with the interests of the ANC. He needs to demonstrate more interest in engaging with people and a commitment to overcoming the Western Cape’s health service challenges.

**NORTHWEST**

**Dr Magome Masike**

Start date: May 2009

**Positives:** Dr Magome Masike visits hospitals and clinics regularly and supports the use of mobile clinics for visits to rural areas.

**Negatives:** Masike has not focused on staffing or building more clinics. Complaints about negligence and unqualified staff have been shared with him, but without any action. NGOs that are providing community education lack training. Regular stock-outs of ARVs and chronic medication are impacting patients at rural clinics.

**Civil society:** Thus far, Masike’s only engagement with members of civil society has been via attendance at World AIDS Day event.

**Provincial AIDS Council:** The MEC is a member and attends, but is not an active participant.

**Report summary:** The MEC has failed to resolve the significant service delivery problems in the province, including lack of access to treatment.

**FREE STATE**

**Dr Benny Malakoane**

Start date: February 2013

**Positives:** Malakoane has integrated the provincial TB and HIV programmes.

Since he came to office, Malakoane spends too much of his time in meetings with departmental heads and managers. When the Premier of the Free State showed no interest in chairing the Provincial AIDS Council, Malakoane took on this responsibility. The province committed itself to a target of getting 40,000 people on HIV by the end of 2014. Its total already stands at 140,000.

**Negatives:** He is refusing to make funds available for a civil society forum despite a commitment from the previous MEC. He has also failed to address the problem of drug stock-outs of ARVs, TB drugs and medications for chronic conditions. Budget constraints mean that departmental posts are frozen, emergency services have collapsed, and that health managers are unable to travel because they have no fuel for their vehicles.

Malakoane has failed to make agreed funds available for HIV Counselling and Testing campaigns. A TAC memorandum submitted to him on the TAC Day of Action received no response. Two weeks after his appointment, the MEC faced charges of corruption in connection with his work as a municipal manager.

**Civil society engagement:** Malakoane’s level of engagement is declining. He has been unreachable for the past few weeks.

**Provincial AIDS Council:** He chairs the Council but has not created an environment in which stakeholders feel they can participate. He has met only once with TAC during a Provincial AIDS Council meeting.

**Report summary:** He is not performing well and the future looks bleak.

**MPUMALANGA**

**Candith Mashego-Dlamini**

Start date: February 2013

**Positives:** Thirty park homes have been placed at clinic sites and 180 ambulances were purchased in May. Eye care programmes have started at several schools.

**Negatives:** Has failed to attract doctors to the province or fast-track urgently needed facility renovations.

**Civil society:** She met with members of civil society. She met with members of civil society and has met with TAC in August to engage on issues related to Gert Sibande, a pilot NHI district site, and will meet with the TAC for treatment. We feel his response has not been satisfactory and that he does not address our concerns in his letter.

**Provincial AIDS Council:** Mashego-Dlamini has met with members of civil society. She met with TAC in August to engage on issues related to Gert Sibande, a pilot NHI district site, and will meet with the TAC for World AIDS Day event.

**Civil society:** She met with members of civil society and met regularly with TAC.

**Provincial AIDS Council:** The MEC is a member and attends, but is not an active participant.

**Report summary:** The MEC has failed to resolve the significant service delivery problems in the province, including lack of access to treatment.

**LIMPOPO**

**Current MEC:**

**Dipuo Letsatsi-Duba**

Start date: July 2013

**Report summary:** Recently appointed, Letsatsi-Duba has made substantial promises but not yet fulfilled them.

**Former MEC:**

**Norman Mabasa**

Time in office: February 2012–July 2013

**Positives:** Gaining access to Mabasa was easy.

**Negatives:** He was politically naive, leading to his removal.

**Civil society:** He was responsive to members of civil society and met regularly with TAC.

**Provincial AIDS Council:** Norman Mabasa was involved in Provincial AIDS Council meetings and understood what the structure needed to achieve.

**Report summary:** An MEC who responded to issues raised by TAC throughout his term. We were sorry to see him go.
AIDS Councils in need of care

Vinayak Bhardwaj

In October 2012, the SA National AIDS Council (SANAC) committed itself to a wide range of initiatives designed to improve its effectiveness and that of the country’s HIV prevention efforts. Measures included increasing national funding for prevention activities, the reinvigoration of provincial AIDS Councils, and the broadening of representation within the body’s leadership.

Among others, the National Strategic Plan states clearly: “Governance and reporting arrangements will start at ward level through districts and municipalities to provincial AIDS councils and finally to SANAC. There will be a clear guiding framework to support implementation and set out expected roles and responsibilities.”

One year after the reforms were announced, SECTION27’s snapshot survey of provincial structures reveals that SANAC has achieved only limited success. While provincial councils are now established in each of the provinces surveyed by SECTION27, their functionality and responsiveness varies significantly and is mostly poor.

With the exception of Limpopo, survey respondents indicated that provincial AIDS Council meetings are held regularly, with most being held quarterly. Meetings are chaired by the respective provincial premiers, except in the Western Cape where it is headed by the MEC for Health, Theuns Botha.

In the Eastern Cape, KwaZulu Natal and Mpumalanga, provincial AIDS Council meetings appear to be co-governed by both members of civil society and the provincial government. Task teams of provincial government officials have been appointed in KwaZulu-Natal and Mpumalanga, with the implication that meetings are run, he says: “Some of the organisations represented have no constituency … We need organisations that have a real constituency to be represented.” Milambo hopes that once the (mid-term) review of the National Strategic Plan (NSP) is conducted, improvements will be possible.

The scope of the activities performed by each provincial AIDS Councils has varied. In the Eastern Cape, a provincial spokesperson indicated that the National Association of People Living with HIV/AIDS (NAPWA) had piloted a ‘Stigma Index’ (to measure levels of stigma and discrimination). Results were disseminated to the province via the council with a view to better informing policies and interventions.

In KwaZulu Natal, provincial AIDS Council support has been given to major initiatives, including the HIV Counselling and Testing Campaign (HCT), the PEPFAR-supported Zazi campaign aimed at young HIV-positive women, and the Hlonjanje campaign. The Council has also supported a ‘Sugar Daddy’ project which warns against the risks of cross-generational sex, as well as a World AIDS Day event.

Provincial infant mortality levels are being monitored with the additional support and guidance of research institutions when needed. Progress in the Limpopo Province has been less encouraging. Meeting cancellations have meant that the Council had not yet developed adequate monitoring instruments, and still appears to have no advisory role to the provincial government. Similarly, even after four meetings this year, the provincial AIDS Council in Mpumalanga had not developed specific monitoring and evaluation components, and the Council does not appear to be engaged yet in any specific activities.

In the Western Cape, council discussions have focused largely on issues related to new developments in AIDS and TB research, including male circumcision and genetic methods of detecting TB. While initial work related to circumcision campaigns has been undertaken, wider debate about whether such campaigns potentially infringe upon traditional circumcision culture may limit further activity. SECTION27’s survey may not provide an in-depth picture of the provincial AIDS Councils, but it indicates that their progress has been inconsistent and, at times, far from adequate. Many lack a clear vision of what they wish to achieve and have been weakened by political wrangling and interference. A year on, SANAC’s vision of improving the effectiveness of its provincial structures has not been fulfilled.

NSP Review did approach SANAC for comment on the importance and role of AIDS Councils, but received no response.

“...SECTION27’s snapshot survey of provincial structures reveals that SANAC has achieved only limited success.”
Government leaders and the SA National AIDS Council were due to host their World AIDS Day events in Mpumalanga’s Gert Sibande district while activists were planning a protest. However, once the leftover food is cleared, the banners rolled up and the marquees trucked away and the delegations drive off in their slick vehicles, a district in desperate need of serious intervention remains behind. Kerry Cullinan of Health-e News Service turns the spotlight on the district.

According to The 2011 National Antenatal Sentinel HIV & Syphilis Prevalence Survey in South Africa, 46% of pregnant women in the Gert Sibande District of Mpumalanga were HIV-positive – the highest rate in the country. Unsurprisingly, The District Health Barometer (DHB) 2012/13, published by the Health Systems Trust, paints a picture of a district burdened by weak and dysfunctional management. Approximately one million people depend on a district that appears to lack adequate skills, commitment and staff, and is unable to cope with the challenges it faces.

While the reduction of maternal mortality is one of the highest priorities of the national Department of Health, maternal mortality in the Gert Sibande District (the number of women dying during pregnancy or shortly after giving birth) has more than doubled from 76.4 deaths per 100,000 live births in 2011/12 to 187.6 deaths in 2012/13. (The national average is 132.9 deaths.) Research shows that some 40% of maternal deaths are preventable, particularly if care during pregnancy is good. This rapid rise in the number of maternal deaths within a single year therefore clearly indicates that the services in this district are inadequate and that case management is poor. Achieving the Millennium Development Goal of reducing maternal mortality to 38 deaths per 100,000 births by 2015 will not be possible in this region.

Studies have indicated that rates of cervical cancer are higher in women with HIV. According to national guidelines, all HIV-positive women should be given a pap smear test to check for cervical cancer as soon as they are diagnosed with HIV. However, in the Gert Sibande District, less than half (45.8%) of this target group were screened, a rate nearly 10% lower than the already poor national average of 55.4%.

The MEC’s response to these specific complaints noted that:
- “Almost half of the posts for doctors remain vacant (a shortage of 557 people), while almost 60% of specialist posts (90 personnel) and 21.2% of professional nursing posts (1,331 personnel) remain unfilled. The Health Facilities Improvement Team reported that ‘Mpumalanga [Province] has the second lowest staffing level of doctors to patients (2.31 doctors per 10,000 [patients])’ and that it would cost R2.1-billion to bring the province in line with national averages.
- “Despite these staff shortages, the Gert Sibande District has slashed expenditure on its eight district hospitals by almost half since 2004/5. Although primary healthcare clinics in the province are struggling to attract health workers. Almost half of the posts for doctors remain vacant (a shortage of 557 people), while almost 60% of specialist posts (90 personnel) and 21.2% of professional nursing posts (1,331 personnel) remain unfilled.”
- “Ermelo’s ICU has been closed due to renovations to an adjoining building that had made the unit unsafe. The Rob Ferreira Hospital was due to protest against “the appalling conditions under which healthcare workers are working,” staff shortages and delays in making appointments. Specific grievances were raised about particular health facilities, including the fact that the intensive care unit (ICU) at Ermelo Hospital was not functioning, that patients at the hospital were not getting proper food, that delays had occurred in the construction of the Rob Ferreira Hospital, and that stock-outs of medicines were occurring.
- “Water supplies at the Rene Clinic were not functioning properly because a tank which had been supplied was broken. A new borehole would be drilled during the next financial year.”

“...maternal mortality in the Gert Sibande district has more than doubled from 76.4 deaths per 100,000 live births in 2011/12 to 187.6 deaths in 2012/13.”
Putting primary health care into practice

Leanne Brady, Rural Doctors’ Association of South Africa

Successfully managing the challenges posed by diseases such as TB and HIV depends on the establishment of a strong and well-integrated health system.

Primary health care (PHC) re-engineering is the cornerstone of the national health insurance (NHI) plan. In the Eastern Cape, a Service Delivery Improvement Plan (SDIP) has prioritised the revitalisation of primary health care (PHC) services. Improvement is urgently needed. The Peddie Region case study describes problems that are common across the province: the PHC system is fragmented and many of the activities and services provided are poorly coordinated. As the Plan acknowledges, the PHC system in the Eastern Cape has been hampered by issues such as critical staff shortages (especially in rural areas), poor infrastructure, and inefficient internal processes relating, for example, to supply chain management.

Overcoming these barriers requires addressing all these factors in order to strengthen the PHC system. This should include outreach programmes offered by district hospitals to PHC clinics. The focus should be on preventing disease, which requires an active health promotion program, and better deployment of mobile clinics to areas without permanent clinics. It is important to recognise that each health district is different and has specific disease priorities and implementation challenges. While the strengthening of the area’s PHC system needs to be overseen at the provincial level, it is also important that power is not too heavily centralised so that district-specific strategies can be developed and implemented.

Ideally, a PHC system must function as an integrated unit. Referring patients from clinics to hospitals must be a smooth and simple process, and reports should be sent to clinics afterwards to allow for continued, seamless management by PHC nurses. PHC clinics should be nurse-led, but regular doctor visits provide a safety net for nurses when patients present with conditions that lie beyond their scope of nursing practice. They also provide opportunities for onsite training and mentoring. Onsite doctor visits also contribute to a reduction of unnecessary referrals to hospitals because many conditions can be investigated and treated in a PHC setting instead. Not having a doctor onsite leaves both nurses and patients more vulnerable and leads to patients traveling large distances to receive further treatment at hospitals.

However, improving the Eastern Cape’s PHC system requires more than just increasing the number of clinic outreach visits by doctors. District hospitals and local clinics must be embedded within the communities they serve. All health team members should be involved in collecting and responding to data so that they are able to see improvements directly and identify challenges. Motivating staff in this way allows for better monitoring and improved patient management. Active community participation should also be encouraged. This can be achieved through involving communities in the planning and delivery of healthcare initiatives and by employing teams of well-trained and supported community health workers.

The Peddie region: A case study

The Peddie region has 23 clinics and one district hospital. On average, fewer than 15 of the clinics are visited by a doctor on a regular basis. Some of the clinics that no longer receive visits were previously attended by two primary health care (PHC) doctors. In 2012, one of the doctors passed away and the other retired. Neither has been replaced. Currently, most of the outreach to the clinics in the area is conducted by doctors from the Nompumelelo Hospital. Staff shortages at the hospital, however, mean that the number of clinics visited by doctors will be reduced further to just ten from 2014. This means less than half of the clinics in the Peddie region will be receiving regular visits.

An informal anonymous survey has revealed that the majority of the clinics in the Peddie region are visited only once a month and that, on average, doctors see 10–15 patients per visit. Drug shortages at the clinics are still ongoing and doctors bring their own supplies so that they can provide adequate treatment. Very little nurse training is done during the clinic visits. Feedback during the survey indicated an overwhelming desire for more frequent doctor visits and for more onsite nurse training. It should also be noted that many of the clinics chose not to participate in this survey.

The PHC system in the Peddie area is clearly inadequate but it has improved significantly over the past ten years. In 2000, clinics lacked even basic drugs and (according to the survey) had not been visited by a doctor in years. It is important to acknowledge that progress has been made, much of which could be attributed to the rapid scale-up of HIV services. While approaches to the HIV epidemic have been disease-specific, these positive changes have created a platform on which to build a stronger health system that delivers services in a more comprehensive and sustainable way.

AUTHOR ACKNOWLEDGEMENT

Many thanks for the contributions made by doctors, nurses and community health workers in the Peddie region, the identities of whom shall remain anonymous.

“...the PHC system in the Eastern Cape has been hampered by issues such as critical staff shortages (especially in rural areas), poor infrastructure, and inefficient internal processes relating, for example, to supply chain management.”
Patents: reform or lose

Lotti Rutter, Treatment Action Campaign

Achieving the National Strategic Plan (NSP) objectives depends on the effective use of the national health budget. But is there sufficient emphasis on value for money in the health sector at a time when South Africa is struggling to meet its targets of placing 80% of eligible patients on ART and reducing TB deaths by 50%? Or is money being wasted lining the pockets of the pharmaceutical industry that manipulates the system to make ever-increasing levels of profit?

According to the agreement on Trade Related Aspects of Intellectual Property Rights (TRIPS), member countries of the World Trade Organization (WTO) must respect a period of patent protection lasting 20 years. During this time, a patent holder maintains exclusive rights to their product. This lack of a competitive market allows pharmaceutical companies to charge unaffordable prices in order to maximise profits – meaning life-saving medicines remain inaccessible.

The success of the ART scale-up in South Africa to date was only possible because of major price drops achieved through the introduction of generic competition. The cost of a standard first-line HIV drug regimen dropped from as much as R100,000 per patient per year (ppy) in the 1990s to less than R1080 ppy in the public sector today. These changes were largely the result of individual cases of litigation or complaints to the Competition Commission; yet we cannot rely on these approaches to ensure access to newer medicines. Instead we must utilise legal safeguards outlined in the TRIPS agreement to improve access to medicines more broadly. Whilst many other countries have used these pro-public health measures, South Africa has yet to amend its patent laws to incorporate them. In contrast South Africa blindly hands out drug patents without substantively examining them. In 2008 alone South Africa granted 2,442 pharmaceutical patents – almost exclusively to foreign companies, whilst Brazil only granted 278 pharmaceutical patents between 2003 and 2008. A University of Pretoria study found that 80% of patents upheld in South Africa do not meet its patentability standards. This type of excessive patenting – including granting multiple patents on new forms, new uses and new formulations of an original compound – maintains artificially high prices for extended periods of time and is hugely problematic for public health.

The Department of Health spent R5 billion procuring pharmaceutical products in 2012, indeed imported medicines are the fifth largest driver of South Africa’s trade deficit. By volume, South Africa imports most of its medicines in generic form from India, and the majority of its active pharmaceutical ingredients from China. Yet despite this, branded medicines remain the significant driver of this expenditure.

With time these costs will inevitably increase. Demand will rise as additional eligible patients are initiated on life-long treatment in line with NSP targets, at earlier CD4 counts in accordance with changing treatment recommendations. As resistance to treatment develops, people living with HIV will be shifted to second or even third-line regimens. Many of which remain under patent protection – the current third-line option costs R18,000 ppy. Unless we redress the imbalance in the patent system, costs will rise sharply.

In addition to creating access barriers, patents also impede innovation. If pharmaceutical companies continue to profit from making minor modifications to existing medicines, why would they invest in riskier, more expensive R&D? Under the existing patent system, R&D is motivated by the reward of high profits attained through patents. Inevitably, there is little incentive to develop drugs that are going to be consumed primarily by the poor. The dire state of drug resistant TB treatment highlights the neglect caused by this system.

“Every Rand spent on branded medicines is money diverted from the wider health system.”

Every Rand spent on branded medicines is money diverted from the wider health system. Is it cost-effective to procure medicines with hugely inflated price tags despite the existence of legal flexibilities to reduce these costs? Or is it morally and constitutionally reprehensible to put foreign pharmaceutical profit above people’s lives? The government is attempting to address this imbalance. In September the Department of Trade and Industry (DTI) released a long awaited draft policy, which in part aims to incorporate TRIPS flexibilities into national patent law in order to improve access to affordable, quality medicines in the country. The TAC, SECTION27 and MSF jointly submitted recommendations to improve the ‘Draft National Policy on Intellectual Property’ (DNPIP) with support from over 150 civil society organisations, academics and experts globally. Without major reform of the South African patent system as outlined in our recommendations the NSP targets will remain a pipedream. The current patent system fails local industry and impedes innovation. Most seriously, it costs lives.
From targets to communities: citizen journalists track the NSP

Sibongile Nkosi, Health-e News Service

South Africans are hit hard when government plans do not translate into action. But now, Health-e News Service is using an innovative programme to give communities a voice – and to help people track the progress of the NSP from the ground up.

OurHealth is a citizen journalist programme that started with the placement of community journalists in five of some of the country’s worst performing districts, each of which were also National Health Insurance pilot sites. There are now 20 citizen journalists stationed across the country.

Already, OurHealth journalists have broken several major stories in the Eastern Cape. These include the closure of the Vilage Clinic at Lukusiki and the drug depot strike at Mthatha which prompted an emergency intervention in December 2012 by the Treatment Action Campaign and Doctors Without Borders. OurHealth’s citizen journalists are also helping to monitor NSP goals.

NSP TARGET: Initiate at least 80% of eligible patients on antiretroviral (ARV) treatment. At least 70% must be alive and on treatment after five years. Achieving this NSP target will depend on people living with HIV having access to treatment and to drug supply chains which function properly. In October 2012, Goso Forest Clinic in the OR Tambo District in the Eastern Cape ran short of medicines, including ARVs. OurHealth investigated this case, as well as four other ARV stock-outs, and discovered and reported it to the Department of Health.

OurHealth has also partnered with the Southern African Regional Programme on Access to Medicines to prevent stock-outs from occurring. We are conducting monthly monitoring of essential medicine stocks in almost all of the 11 NHII pilot districts. The findings are also being shared with the Stop Stock-outs Project.

NSP TARGET: 1 600 000 men circumcised by 2016/17. To achieve this NSP target, local clinicians need permission to allow professional nurses to perform MMC under the supervision of a doctor.

NSP TARGET: distribute one billion male condoms annually by 2016. Although the NSP has set high targets for the number of male condoms to be distributed, OurHealth has reported that many facilities face ongoing shortages or stock-outs. In the Gert Sibande District, local non-governmental organisations also face problems in accessing and distributing condoms, and this is jeopardising the district’s ability to meet its distribution targets.

NSP TARGET: Reduce the number of TB deaths by 50%. While some districts have improved the TB services they provide, OurHealth journalists have found that others are struggling. TB test results provide an entry point for life-saving treatment. But in Johannesburg, tests results for many Soweto patients were delayed recently due to the introduction of a new information management system. These delays also affected results for HIV, CD4 counts and pap tests. In contrast, the Sesifuba TB Hospital in Mpumalanga, has reduced both its TB death and its default rates in the last year. According to one nurse, this is because the hospital has managed to better integrate its TB and HIV services.

NSP TARGET: 90% of clinics will provide services after hours or on weekends by 2016. OurHealth journalists have noted that the length of opening hours at clinics are still a problem in many parts of the country. In Manyoni District, for example, clinics were closed for most of the week, which made it difficult for the local community to access HIV and antenatal care.


Structural barriers that make it difficult for sex workers to access healthcare also need to be addressed.

Making the

NSP SWEAT

Sally-Jean Shackleton and Maria Stacey, Sex Workers Education and Advocacy Taskforce (SWEAT)

Sex workers face significant barriers to accessing health services, experience a disproportionate burden of disease, and are subject to daily human rights abuses. Since the launch of the second NSP, it appears that there is a new political commitment to improving their lives, and to providing better access to HIV and sexually transmitted infection prevention, care, treatment and support.

The National Sex Worker Symposium, held in 2012 was a mark of progress in programming for sex workers. The symposium engaged researchers, practitioners, policy makers and sex workers themselves in discussions on best practice and innovations related to sex worker healthcare and support. Following shortly after this, SANAC brought together a sex technical working group made up of practitioners and experts to develop and finalise the National Sex Work Plan. The Plan, now finalised, includes realistic health indicators for this population group.

SANAC funded a rapid sex worker population size estimate, and at all levels of government, people are grappling with how access to health care for sex workers can be improved. Technical support and guidance are being sought from organisations such as SWEAT and members of the Sex workers Sector. The expertise being provided is significant and support for these activities is essential to enable the Sector and member organisations to respond.

Poor coordination between sex worker projects remains a problem: several are not aligned to a common monitoring or evaluation framework and assessing their progress is difficult. This means that service delivery standards may vary significantly from project to project, and that the good work being achieved may be going unrecognised. Better project coordination is still needed at SANAC and work related to the sex work sector needs to be better supported at both the provincial and local level. Another major impediment to providing effective programmes for sex workers is the continued criminalisation of sex work. Evidence shows that criminalising sex workers undermines efforts to address their health needs. While SANAC can’t achieve decriminalisation on its own, it has a responsibility as Government’s advisor on HIV, to make recommendations for legal reform. Despite efforts to address this issue, and agreement in the Civil Society Sectors, SANAC Plenary has failed to make a clear recommendation to government about the need to decriminalise sex work. The Human Rights Technical Task Team has held discussions about the issue, and there is still resistance from some quarters to the clear evidence that continued criminalisation impairs sex workers’ access to justice and health, and contradicts South Africa’s efforts to address HIV.

Structural barriers that make it difficult for sex workers to access healthcare also need to be addressed. Interventions that facilitate sex worker empowerment, self-organisation and human rights protections all have the potential to reduce stigma, increase the demand for services, and inspire sex workers to participate more in their own care. The newly convened Social and Structural Drivers Technical Task Team will focus on these complex issues. The previous National Strategic Plan on HIV, STIs and TB failed in its efforts to improve the lives of those in key vulnerable groups. We are hopeful that the implementation of the current NSP will focus not just on the easy gains, but also on the harder issues that may require more courageous transformation – like legal reform and sex worker empowerment.
Success depends on increased and efficient spending

Thoko Madonko, Budget and Expenditure Monitoring Forum

South Africa’s Constitution states clearly that all citizens have the right to access health services. This means that our government has a constitutional responsibility to provide healthcare, and an obligation to plan, cost and implement public health programmes. Monitoring budget allocations and expenditure related to the National Strategic Plan on HIV, STIs and TB (the NSP) is therefore vital because such indicators help to tell us whether the government is succeeding or failing to meet these duties.

The Budget and Expenditure Monitoring Forum (BEMF), a group of civil society organisations that provides an ongoing evaluation of the NSP, recognises that considerable progress has been made since 2004 to increase levels of access to treatment for HIV & AIDS, STIs and TB. By mid-2012, for example, over 2 million people of the estimated 6.4 million people living with HIV/AIDS in South Africa were on antiretroviral therapy (ART). In addition, civil society and political pressure has led to a reduction in the costs of medicines and medical supplies. A more competitive bidding process has allowed the South African government to reduce the cost of ART drug procurement to the lowest price anywhere in the world (approximately R1170/US$113 per person per year for fixed-dose combination treatment). As a result, antiretroviral treatment expenditure has been reduced by 53% since the last tender.

But the first NSP of 2007-2011 was marred by a failure to properly cost or budget for specific spending on HIV, STIs and TB. Both nationally and provincially, costing was incomplete, and poorly coordinated resulting in what appeared to be nothing short of a random approach to financing NSP related programs. Ultimately, these weaknesses hampered the achievement of the NSP targets, a failure that South Africans could ill afford given the scale of the challenges the NSP sought to address.

The global financial crisis has also impacted upon the government’s ability to achieve the targets of the NSP. For instance, the percentage of government expenditure on health remains at 11.3%, well below the 15% pledged by South Africa in the Abuja Declaration of 2007. The BEMF acknowledges that the total share of the health budget spent on HIV & AIDS has increased, and that this will rise to approximately 10% in 2015/16. But unless the overall health budget grows to accommodate such increases, other health services are likely to suffer. Spending on HIV/AIDS, STI and TB cannot be seen in isolation, and other spending priorities in the health sector remain vital, such as infrastructure and maintenance, support for rural health, emergency medical services, non-communicable diseases, and preventive and rehabilitative services.

The government, as a matter of urgency, must ensure that any cost-cutting measures (often referred to by Treasury as “maintaining expenditure ceilings”) are not at the expense of South Africa’s health services. The BEMF recommends that Treasury revise the budget ceilings set for health and introduce above-inflation budget increases to both protect and enhance the delivery of health services, including HIV & AIDS, STI and TB. Without real increases in the overall health budget, it is unlikely that the NSP will be fully implemented. The BEMF believes that to pursue a policy of containing expenditure is in health-related budgets would be both retrogressive, unlawful, and a breach of the government’s constitutional obligations to provide access to healthcare services.

A special edition of the NSP Review published in September 2013 bore witness to the collapse of the Eastern Cape public health system. Death and dying in the Eastern Cape: An investigation into the collapse of a health system showed that the failure in the province was entirely predictable. For over a decade, department officials and politicians have ignored, and in some cases perpetuated, conditions that cause the death and dying. Their failures continue to violate the rights and endanger the health and lives of six million people.

The Minister steps in

Six days after the march, the national Minister of Health announced specific commitments for interventions in the Eastern Cape (a summary can be found at: www.echealthcrisis.org) These initiatives focused on the OR Tambo District, a National Health Insurance pilot district, and Holy Cross Hospital. The Minister also made a number of commitments related to the rest of the Province.

The Province lags

The provincial health authorities failed to respond to the memorandum within the requested timeframe. Instead, on 17 October, the Department sent the Coalition a five page document titled Eastern Cape Health Systems Intervention. It proposed interventions including changes to the supply chain for medicine and supplies, equipment purchases, infrastructural maintenance, payments of accrued debt owed to staff, the improvement of provincial leadership and management, the development of a five-year budget plan, and the strengthening of institutional capacity and governance.

In response, the Coalition provided in-depth commentary on the document. The document and the Coalition’s analysis are available at www.echealthcrisis.org

The Coalition wrote that it was “heartened that both the national and provincial departments of health have now recognised healthcare services in the Province as a crisis needing urgent attention. It also, however, noted that the “ECDoH document is not remotely what the Constitution and the Coalition require in terms of a plan to address the health crisis in the Province.”
In sum, the Coalition explained that a proper, lawful plan to turn around the healthcare system would need, amongst other things, timeframes, milestones, measurable indicators and a budget.

Parliament steps in

In late October and early November 2013, the provincial and national parliamentary portfolio committees on health called for hearings on the Eastern Cape health crisis. They summoned the Minister and the MEC as well as the Coalition. Committee members were dismayed at the issues the Coalition had publicised. Some even called for or hinted at the MEC’s resignation. The Coalition committed to working with the department and parliament to fix the healthcare system.

The way forward

The Coalition will continue its campaign for the department to develop and implement a comprehensive plan to fix the healthcare system in the Eastern Cape. It will continue to challenge the national Minister and the ECDoH about shortcomings in the system and their interventions in it as well as make efforts to work with the departments to address the shortcomings.

Constant monitoring will be critical to ensure that current and future commitments to change become realities on the ground. Health professionals and healthcare users should also contribute to the monitoring process. Doing so will enable us to hold the departments accountable for fulfilling the constitutional right to access to health care services in the Eastern Cape.

The Constitution requires a real plan!

In its analysis, the Coalition provided a useful summary of what the Constitution requires of government action. It wrote:

The Constitution requires that a plan to fix the healthcare system in the Province and fulfil constitutional rights, particularly the right to health, must be reasonable. The reasonableness of the plan may be assessed by criteria that include the following:

- It must be reasonably conceived and implemented.¹
- It must be capable of facilitating the realisation of the right.²
- It must be comprehensive and coherente.³
- It must be coordinated in terms of Chapter 3 of the Constitution. This means it must be determined by all spheres of government in consultation and that each sphere must accept responsibility for the implementation of particular parts of the plan.⁴
- Appropriate financial and human resources must be made available for the programme.⁵ Budgeting duties apply to national, provincial and municipal governments in appropriate circumstances.⁶
- It must be balanced and flexible⁷ and make appropriate provision for short-, medium- and long-term needs.⁸
- It must be transparent, and its contents must be made known effectively to the public.⁹
- It must make rights more accessible to a larger number and wider range of people as time progresses.¹⁰
- It must make short-term provision for those whose needs are urgent and who are living in intolerable conditions.¹¹
- It must be conceived of with an appropriate understanding of constitutional and statutory obligations.¹²

¹ Government of the Republic of South Africa & Others v Grootboom & Others 2000 (11) BCLR 1169 (CC) para 40-43. 2 Id para 41. 3 Id para 39 and 40. 4 Id para 40 and 60. 5 Id para 30. 6 City of Johannesburg Metropolitan Municipality v Blue Moonlight Properties 39 (Pty) Ltd and Another 2012 (2) SA 104 (CC) at para 57 and 67. 7 Grootboom para 68, 78 and 95. 8 Grootboom para 43. 9 Minister of Health and Others v Treatment Action Campaign and Others para 123. 10 Grootboom para 45. 11 Grootboom para 44 64, 68, 99; TAC case para 78. 12 City of Johannesburg Metropolitan Municipality v Blue Moonlight Properties 39 (Pty) Ltd and Others (2011) ZACC 33 at para 74. 13 S Liebenburg Socio-Economic Rights: Adjudication under a Transformative Constitution (Juta, Claremont, 2010), p 152.
Did you get all of your medication today?

Uyitholile yonke imithi yatho namhlanje?

STOP STOCKOUTS
084 855 7867
Report Medicine Stock Outs

SMS • Please Call Me • Phone • What'sApp • Email: report@stockouts.co.za

Photo Credit: Bithin Das

1. TELL US!
If you did not receive all your medicine today, let us know.

2. ACTION
We will help you and your clinic look into the problem.